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Abstract

The label of 'intellectual disability' can be a very blurred concept, because for those on the borders, their label often arises from the interaction of the individual with their environment, from their socio-economic status, and from the social role which they choose to undertake. This paper explores the contested notion of intellectual disability in the context of people who have been in trouble with the law in England, and contrasts their situation with that of people who have been protected by best interests decisions under the Mental Capacity Act (England and Wales). People who are on the 'borderline' of having an intellectual disability, like any citizens, have a range of intersecting identities. Drawing on the notions of 'interactional' disability theory, we reflect on the shifting, relative nature of intellectual disability, and the need for the law to focus on support needs, rather than on impairment.

The blurred edges of intellectual disability

Introduction

They didn't ask me if I had a learning difficulty [intellectual disability] when I got to prison, and I didn't tell them because I didn't know. But I think if I had known, I still wouldn't have told them as people with learning difficulties get targeted in prison. I couldn't read the rules and regulations in prison which made me nervous, but my cell mate was very good, he explained things to me. The prison

officers were ok; they kept an eye on me. I did English and maths classes whilst inside, I found them really difficult, but because I was only inside for two weeks, they didn't really help me.

When I came out, I started getting things sorted. I moved out of my house and into a youth care home, they did an assessment there and told me I have a learning difficulty. That really shocked me, but I started getting a bit of support then, not a lot, but some.

These are words from a UK research study about people who had been in trouble with the law (Williams, Mason et al., 2014). We will refer to this participant here as Andrew. He was someone who, in his own words, had a learning difficulty. Terminology in this area is often ambiguous, but the words 'learning difficulty' for Andrew and others like him in the UK could be equated with the international term, which we will use in this paper, 'mild intellectual disability' (ID). Andrew told us that he had grown up in care homes and lived in a deprived socio-economic area, without the support of a wider family structure. Since he was not eligible for social care services prior to his spell in prison, he claims that he simply had not known about his impairment. The assessment he had is uncritically accepted by him as leading to a firm truth about his impairment; he is not denying his disability, but accepts its underlying reality, albeit with a degree of shock.

A related story about the blurred edge of intellectual disability was told to us by social and health care practitioners in a previous research study, which concerned the implementation of the 2005 Mental Capacity Act (MCA) in England and Wales

(Williams, Boyle et al., 2013). The Act seeks to clarify questions of capacity, by adhering to a decision-specific principle; however, it only applies to someone who has 'an impairment of or disturbance in the functioning of their mind or brain' (such as an intellectual disability) sufficient that the person lacks the capacity to make a particular decision. In other words, in the case of people with intellectual disability, the diagnosis has to precede any action under the MCA. A person with cognitive impairment can only be assessed as lacking capacity in relation to a particular decision, must receive full support to make their own decisions wherever possible, and is in principle allowed to make risky or unwise decisions, providing he or she has capacity. One of the cases we followed up in our study involved a young man 'Derek' with a borderline intellectual disability, whose story is anonymised here. Unlike Andrew, Derek lived in one of the most affluent areas of England, and his family had advocated for him to receive local authority funding to move from the family home and into a group living arrangement, with some staff support during the day. He could clearly make many decisions for himself, and had been choosing for some time to go out at night, and spend time around drug dealers in the centre of the city where he lived. This was a long story, but it ended with Derek being assessed as lacking capacity to understand the consequences of his actions, and therefore needing more comprehensive support services in order to manage his own life safely. The law was used to make a 'best interests' decision, albeit with much discussion with Derek himself, and those around him. Autonomy, in other words, was only acceptable for Derek, as long as he was not putting himself at risk. However, for every 'Derek' there will be many others like Andrew, who neither benefit

nor are restricted by the support and protection that can flow from being identified as someone with an intellectual disability.

This paper aims to reflect on the assumptions underpinning these discourses, with an eye to raising questions about the adequacy of disability studies theory for those who may fall on the borderline of intellectual disability. We approach the topic as qualitative researchers, who have worked in different ways alongside people with the label of 'intellectual disability' in research studies and elsewhere. We are acutely aware that not only the criminal justice system and the Mental Capacity Act, but also a raft of English policy (DH, 2012), and both UK human rights statements and instruments (Equality Act, 2010) and internationally the UN Convention on the Rights of Persons with Disabilities (2007) are premised on the assumption that we can know who falls within their remit, precisely on the grounds of being disabled or having a 'protected characteristic'. However, there has recently been critique of mental capacity legislation, on the grounds that it is at odds with Article 5 of the UN Convention, discriminating against rather than 'protecting' disabled people (Martin et al., 2014). The question of 'who is disabled?' is therefore a very practical and urgent one to determine in many instances, and this paper explores the blurred edges of disability, in the context of people with the (contested) label of 'intellectual disability'. We are reflecting on these issues precisely because they have been raised by people with intellectual disabilities, in their own lives, just as Andrew did in the opening words of this article: *I didn't tell them because I didn't know.*

Intelligence as the basis of classification

Traditionally, the notion of intelligence testing has underpinned the identification of an intellectual disability (Fredrickson and Cline, 2002: 232-245). Although an IQ test embraces the idea of a continuum of ability, it is based on the idea that a score below one standard deviation from the mean (with an error of + or – 5) is not just part of ordinary social variation, but constitutes an impairment that can be diagnosed, in a way that is analogous to the diagnosis of a medical condition (Gillman et al., 2000: 251). The practice and the theoretical basis of IQ testing have been criticised both by theorists and by practitioners. For instance, Whitaker (2010) found systematic errors in IQ test application and results. These arguments build on Flynn's (2000) classic critique of IQ testing, in which he noted the systematic bias inherent in IQ tests, resulting in a far higher proportion of African Americans being classified as having 'mental retardation' (sic) than the white population. Flynn concluded that: 'consideration should be given to abandoning IQ tests, in favour of direct tests of impaired adaptive behaviour' (Flynn, 2000: 191).

More recently, the functional aspects of intellectual disability have been acknowledged in England, where the prevailing definition of 'learning disability' since 2001 has recognised both the lifelong nature of the impairment, but also the 'reduced ability to cope': *'a significantly reduced ability to understand new or complex information, to learn new skills; a reduced ability to cope independently, and.... (these difficulties) started before adulthood, with a lasting effect on development'* (Department of Health, 2001)

Underpinning that definition is the idea that individual human beings do ideally 'cope independently', as autonomous functioning persons who do not need others for support (Johnson et al., 2010). What is the person expected to cope with, in order to show that

their ability is reduced? In an increasingly complex world, more and more people have a reduced ability, when dealing for example with the demands of technology or the minutiae of financial services. As argued by McKenzie (2013), it would seem that the concept of intellectual disability is shaped both by the individual but also by their social world, and that the amount of social inclusion and support received will make a difference to the status of intellectual disability. This paper seeks to take this argument a step further, by examining particular legal contexts, where an individual may take up a social role which ratchets up their status as disabled, and their needs for support, as was the case for Derek and for Andrew.

What is disability, what is impairment?

There have been many debates over the past twenty years about definitions of disability (Oliver, 2004, 2013; Shakespeare, 2006). For instance, the claim is commonly made that the social-medical divide does not account for the actual experience of impairment (Crow, 1996; Thomas, 2004) and there are calls to 'bring back the body' into the discussion of disability, or maybe even a sociology of impairment (Hughes et al., 1997). There are also strong arguments about the disabling effects of societal expectations of normalcy (Davis, 1995: 23) and ways in which they might influence the inner experience of being disabled. Those effects can be argued as strongly for people with intellectual disabilities (Cooper, 2013) as for those with physical impairments, and one of the current authors (Williams, 2011) has analysed how the detail of social interactions can draw on and reinforce the incompetence of people thus labelled. Further, there are arguments that intellectual disability (as an impairment) may be socially constructed (Rapley, 2004), just as can be argued in the area of mental health (Williams & Heslop,

2006), although many would argue for a realist core to the concept of intellectual disability (Watson, 2012: 198-9). How then would we know who to count as 'disabled', who might be experiencing an illness, and who may simply not be coping too well?

The experience of impairment is perhaps treated with more subtlety by interactional models, where the symbiotic relationship between impairment and disability takes centre stage. That is the position of the 'biopsychosocial' model of human functioning and disability offered by the World Health Organisation (2002) that underpins the attempt to provide a unified classification system, the International Classification of Functioning, Disability and Health (WHO, 2011). Applying that idea to intellectual disability, it is precisely the conclusion reached by McKenzie (2013) who used q-methodology, asking 85 individuals to record agreement or disagreement with particular statements, reflecting various discourses of intellectual disability in South Africa. Through this process, he identified what he calls an 'interactive discourse':

Within this frame, disability is acknowledged as a mismatch between an individual and their environment and is context dependent. (p. 372)

This echoes Garland-Thomson's (2011) notion of 'misfitting', where a disability is seen to arise from material arrangements, as well as individual differences. McKenzie goes on to argue that competence depends both on the individual and the social environment. Thus the concept of intellectual disability in that view is a malleable one, changing through the life course (Williams, 2013) and also dependent on social conditions, poverty, family support and a wealth of other factors. For instance, it has been shown that those on the edges of the category of ID are much more likely to

be affected by general social determinants such as poverty and deprivation, than the general population (Emerson & Hatton, 2011: pp 12-13), as in fact seemed to be the case for Andrew whose words open this article.

Discourses about labelling

Concerns and challenges about the status of disability are often heard from members of the self-advocacy movement (Williams, 2011; Beart et al., 2005), with the self-identification of people with ID being seen as problematic (Todd and Shearn, 1997; Rapley et al., 1998). In some of these studies, people with ID are seen as active agents in negotiating their own identity, and Williams (2011) analysed interactional data from inclusive research, showing how people stepped into different identities in the course of carrying out research. In all these studies, we can see how the identification of people with ID is dependent both on the social context and culture, as well as the particular demands placed on people at points in their life course.

For instance, more individuals are identified as having some form of intellectual disability (or 'needs') at the stage of formal education than in adulthood (Norwich, 2002); the UK educational system is driven by targets for achievement (Barton, 2003: 61) that place a significant number of students into a category of 'special needs' or SEN (in Warnock's 1981 terms, ten percent of the school population in the UK). However, this status is not maintained in adult life. When people leave school, they enter an adult world where academic demands do not necessarily impinge on their everyday lives, and thus 2-3% of the adult population in the UK is commonly considered to have an intellectual disability of some kind (Hatton et al., 2014), with an even smaller proportion

receiving social care support (pp. 13-14). Andrew would therefore have fallen into that wider pool, only gaining the status of disabled when he had a need for a particular service, a placement in the youth care home, or within the prison system, while Derek, maybe through the active agency of his more socially advantaged family, fell into the smaller core group, thereby becoming eligible for social care. What we can conclude is that, at least for some individuals, an intellectual disability is not a static condition, but is influenced both by the context and by the socio-economic background, age and culture of the individual. It is easy to imagine how radically different the careers and outcomes for both Andrew and Derek might have been had they swapped one or more of these factors. Perhaps the most important difference is the way that the state responded to their risky behaviour, with Derek being spared a criminal record precisely because of his early identification as a person with intellectual disability and the subsequent application of the Mental Capacity Act.

A further facet of the labelling debate is that, in the past, intellectual disability has been linked with criminality, in a way that made the two terms almost synonymous. For instance, the 1913 Mental Deficiency Act in the UK created different classifications, including the nebulous group of the 'feeble-minded', who were considered to be socially 'inefficient', and prone to falling into criminal or morally unacceptable behaviour, just like Andrew and Derek. According to Walmsley et al. (2001), more than 46,000 people were subsequently placed in long-stay institutions as 'moral defectives', away from society, based on those 1913 definitions and their aftermath. The parallels between those institutions and the current day prison system are rather striking (Atkinson et al., 1997; Richardson, 2010). Although we might consider we have moved way beyond that type

of societal discourse, nevertheless Andrew's and Derek's choices about how to self-identify have to be seen in that historical context, where it would be vitally important to balance successfully the risks against the benefits of a disability identity.

Becoming an 'offender with intellectual disabilities'

Although both Derek's and Andrew's experiences thread through this project, Derek's story was told to us by professionals (Williams, Boyle et al., 2013), and did not include his own voice; it is anonymised both in the original report and in the current account. Using the Mental Capacity research as a backdrop, we therefore choose to focus here on the 'Changing Horizons' project. This was a small qualitative research study in 2013-14 (Williams, Swift and Mason, 2014), commissioned by the Guideposts Trust, to inform their support service for people with intellectual disabilities who have been in trouble with the law. Three people participated in three meetings of an advisory focus group and ten individuals (three women and seven men) took part in two connected narrative interviews about their experiences with the criminal justice system (CJS). In the first interview, the researcher followed a loosely structured topic guide, starting from the factors that were most important in the lives and goals of the participants, and allowing them to introduce the 'offence' they had committed as part of their life history. These interviews were recorded, and then transcribed, before being organized by the research team into coherent stories, which were taken back to each participant to read through together and edit. This process did not involve changing the original words of participants, but in places re-arranging material for chronological accuracy, and in other places reducing or deleting elements of the narrative. Narrative analysis was carried out following each person's story as a 'whole', before seeking themes across the stories.

The research received ethical approval from a University ethics committee, and all participants were able to give informed consent to take part in the meetings, and in interviews, and agreed that information about them would be anonymised.

The first warning sign that things may not be straightforward in terms of identity comes generally at the stage of recruiting participants for a research study (see McConnell & Llewellyn, 2002: 299). In this study the recruitment information was passed on to potential participants through key gatekeepers in the criminal justice system (CJS), largely Health employees (forensic teams) or probation services. Immediately we were faced with the problem of how to frame the research to target people with an identified intellectual disability. Both sides of the equation were sensitive, the criminal and the disability identity, and so after some deliberation, we chose to address potential participants with the question: 'Have you been in trouble with the law?' The accompanying information sheet proceeded to list a range of circumstances that might apply to the people we were interested in, including difficulty in understanding information. Apart from our initial three participants who formed a core focus group to advise the research, we had extreme difficulties in recruiting people via the criminal justice system, and eventually turned to self-advocacy groups, organizations representing people with intellectual disabilities in their own right. The way in which we had initially described our target group then seemed instantly to make sense, and ten people readily came forward for interviews. One could speculate that the identity of 'intellectual disability' is a given, in the context of people who have chosen to be members of an organization representing that very group (Goodley, 2000; Williams, 2011: pp 127-42).

If it is hard to know who has an intellectual disability, then it follows that it is extremely difficult to estimate the prevalence of people with intellectual disability in the CJS (Bradley, 2009). For instance, Loucks (2007) uses a very broad definition of 'learning difficulties and disabilities', estimating that this accounts for between 20-30% of male prisoners, and Talbot (2012) found that 25% of adult prisoners had mild intellectual disabilities in the UK. The mix of mental health issues and intellectual disabilities complicated the calculation, and could result in far higher numbers. Hayes et al. (2007) found that one third of the prisoners in one large English penal institution had an intellectual disability, based on specific tests of basic skills. Given that many offences do not result in a prison sentence, it is even harder to know how many minor offenders might count; indeed, the stories we were told in our research indicated that the very plea of being 'learning disabled' was often enough to provoke leniency or protection, rather than a court proceeding. Therefore, the proportion of people with a possible intellectual disability who offend is completely unknown (Talbot and Jacobson, 2010).

Exploring identity issues in '*Changing Horizons*'

What we found in our study concurs with other studies in the UK (Holland, 2004), and in Australia (Boodle, 2013) namely that our participants tended to have come from deprived backgrounds, particularly in terms of emotional security. People who have offended will have spent longer in long-stay institutions (Lunsky et al, 2011), and are more likely to have suffered abuse and neglect as a child (Raina et al., 2013), than those who have not offended. Our participants had very low levels of social capital, from the evidence of their own accounts. In terms of their identity, several of the participants saw themselves equally as victims or offenders. They tended to morph from one to the

other. Peter, for instance, had rung the police when he was harassed by a woman; he was then disbelieved, and accused of seeking to buy sex from the woman:

I had to drop the charges, what else could I do? I couldn't carry on with it if the police were going to make me guilty. [Participant in narrative interview]

One of the striking themes across almost all the eleven stories, both for men and women, was the centrality of close relationships to the offences which had been committed. The times at which people felt they were not coping were always those at which their relationships had broken down, or where they did not have adequate support and advice available; typically for the women in this study, one participant spoke about periods of aggression and wild behaviour, brought about in her view because of her loss of a relationship. Andrew, whose words opened this article, had been drawn into a crime involving financial embezzlement, which he had not understood, but had been suggested to him by a 'friend', whose acceptance clearly mattered to him at the time. This was also precisely what we could see in Derek's story about his encounters with drug dealers. This notion of 'mate crime' (Tilly, 2013) also raises questions of definition and blurred edges, concerning who might be seen as a real friend, and who might be taking malicious advantage of the relationship.

In the advisory group meetings, as well as the individual interviews, we specifically asked about the issue of how people disclosed or were asked about their intellectual disability when they had committed an offence. This was unlike Boodle et al. (2012), where the question of identity was assumed and not explicitly pursued; we may

conclude therefore that the issue became a focus of discussion because of our interest in it. People in the advisory group were equivocal about the value of saying they had a disability, particularly at the point of entering the police station when arrested:

Maybe they'd be more lenient, more softer, but they might be more harder.

They're going to think – he's more stupid, he's more – and I thought, OK – that's why I didn't say anything. [Participant in advisory group]

The tension between acknowledging one stigmatised identity (intellectual disability) is here explicitly balanced against the problems of acknowledging a criminal identity. None of the participants described themselves explicitly as 'criminals', but associated the criminal label solely with the specific occasion(s) on which they had been in trouble, and then come into contact with the police. That contact in itself was sufficient to lay open the possibility of being labelled as a criminal, and in some respects, the disability identity acted as a counter-indication, or certainly a mitigation, to criminality. However, much clearly depended on the way in which disclosure was handled, and the support offered generally outweighed the initial feelings of being discredited. For instance, the label of 'intellectual disability' generally conferred rights to have an appropriate person visit them in the police station, and if they went to court, someone who could act as an advocate and help to explain the system to them. One young man, Stephen, had been drawn into violent behaviour by his brother, who had already been in prison. According to his interpretation of events, when the police asked his father about Stephen's disability status, and accepted that he did have a 'learning difficulty', he escaped with a caution. As far as we were told, no-one in 'Changing Horizons' had experience of the

Mental Capacity Act; yet it was clear how the label of intellectual disability could nevertheless have a protective effect.

The question of identity could be further confused by physical illness or by a mental health problem. One of the features of the criminal justice system for our participants was the presence of medical practitioners, in police stations, in court and in prisons, who were tasked with determining whether or not someone had an intellectual disability. It is interesting how these ideas resonate with the 'Mental Capacity' stories we were told, where health professionals also dominated. For example it was a clinical psychologist who led Derek's best interests process, although he invited a police officer to talk with Derek in the meetings. Further, several of our participants had problems with their physical or mental health which seemed to be confused with their offending behaviour. For instance, people talked of their communication problems being misunderstood as drunkenness, and one person had considerable problems with depression and suicidal thoughts, which led her to be aggressive towards others.

There was a sense of gross injustice in some of the stories from 'Changing Horizons'. Where people were expecting understanding and treatment, they instead were taken as offenders. William, for instance, told us of an incident that was due to his diabetes. A friend ran to get the police, since William was 'kicking out', but, as he said:

It was a medical problem really, and afterwards my sister said we should have gone to the hospital, but my wife didn't have the money to get a taxi down there. [Participant in narrative interview].

Many of our findings related to messages about how to deliver good support within the CJS, and we will not dwell on those here. Suffice to say that the people we met throughout this study had largely lived through their negative experiences of the CJS, and had emerged with appropriate support to take up some very active roles in the community:

I set up a group in my local town, I'm the secretary and my wife is the chairperson. We meet once a month and about 20 people are coming along now. I don't know what I would do without it, I really don't.

[Participant in narrative interview]

Seven of our ten interviewees talked at length about their active citizenship, and the activities they were involved in to support other people, and felt it was most important to give something back to society. Not only did some people cease to need the label of 'intellectual disability', but they also improved their status in moral terms. In particular, we were able to understand through our research how self-advocacy organisations could assist people to take on a new pride in their identity, to support each other and to contribute to society.

Discussion

We started this paper with a consideration of the situations in which legal instruments and rights may depend on being 'counted in' to the category of intellectual disability. As we commented, there are urgent, practical concerns about the need to know who has an intellectual disability, in order to give them appropriate support, and to enable their

protection under laws such as the Mental Capacity Act. What then can we conclude from the examples we have pursued?

There are many people like Derek and Andrew whose identification as disabled will ebb and flow, dependent on the social moment, as McKenzie (2013) pointed out. However, it might be considered by some that these two examples are unusual, and that there *is* a category of people who are more easily defined as being intellectually disabled. We would dispute that there are two camps here. A critical realist account of intellectual disability (Watson, 2012) would maybe allow us to acknowledge that people can and do have a real 'impairment' of the mind, but that nevertheless their social situations, the roles they take up and their interactions with others will all impinge on what they can actually 'be' and 'do' (Thomas, 2004). Thomas' social relational model does not seem to be at odds here with a critical realist account; both acknowledge that impairment does matter, but both provide a way of focusing on the social environment.

If the functional definition of intellectual disability relates to 'a reduced ability to cope independently', then much depends on the precise activity or situation with which an individual is coping. Those in the 'Changing Horizons' project were frequently managing their lives without extra, funded support and instead, like most of us, relied on family and friends to cope with many aspects of their daily lives. It was the nature and quality of that support, combined with their ability to cope, which defined their 'disability', rather than any recourse to IQ testing. For people in this project, the distinction between 'coping' and 'non-coping' was very closely tied to the quality of relationships. This became clear when those same relationships, sometimes because they had turned

sour, led them into decisions and actions which brought them into contact with the criminal justice system.

We return here to the ideas about labelling, autonomy and identity with which we started. Like everyone, the people we have considered in this article take up various social roles, some of which may be more socially 'undesirable' than having an intellectual disability. Their adoption of these roles springs both from their own autonomous decision-making, but also from the social situation in which they find themselves. Poverty, lack of social capital, and emotional insecurity, are all factors that impinged on their lives. The identity of intellectual disability may *not* therefore be the key membership category with which they identify, and indeed may be far less important to them than the status of being poor, having been brought up in the care system, or indeed becoming a self-advocate and a contributing member of their community. Identity, in other words, is a fluctuating concept, and can play itself out in the negotiations and interactions we face in everyday life, both in negative and in enabling ways (Williams, 2011: pp 218-226).

Instead of conceiving of an intellectual disability as something inherent in a person, waiting to be teased out by expert professionals, we need to include in that process a conversation, recognising that people's own sense of who they are does matter. One of the important upshots of taking an interactional view of intellectual disability, is that we can analyse the way people may be 'disabled' by their interactions with others, but conversely also we can see more precisely how those interactions can change and can have very positive consequences for the identity portfolios of participants. An example of that is seen quite clearly in the data presented from 'Changing Horizons', where

positive support for some of our participants resulted in them taking up social roles as self-advocates, supporters and campaigners for change.

Further, we have shown how definitions are relative not just to the individual, but to the social role they are undertaking. This notion chimes with the Mental Capacity Act, which operates on a decision-specific principle, recognising that an individual could have full capacity to make some decisions, while finding others simply too difficult. Whereas previously, the notion of an IQ test was a one-shot approach to knowing who to 'count in' to this category, we now need a more sophisticated appreciation of the label of intellectual disability, which will be relative to the need for support in certain specific situations. One of those, of course, is the criminal justice system. However, there are many others, including becoming a parent (Tarleton & Ward, 2007; McConnell & Llewellyn, 2002) where people can become known as 'disabled' simply because of their need for specific supports, around a social role that is challenging for everyone. Therefore, maybe we do not need to worry about defining the impairment itself, but rather to turn our attention to identifying the social situations in which people may need support, and precisely what that support might look like.

A final word should be reserved here for reflecting on the reach of these lines of argument across a wider spectrum. As Goodley (2011) has commented, we are all in some ways 'disabled', depending on the activities and challenges we set ourselves. It is easy to list the many activities in life which any of us 'cannot' do, because of our inherent limitations, and maybe some of those are activities which we would not choose to do, as Swain and Cameron (1999) pointed out. We need to be cautious that definitions of intellectual disability do not create two camps of individuals, those who

need particular adjustments and supports, and those who do not. Maybe something similar to the protective principle of 'best interests' comes into play for all of us on a daily basis, through the concerns of significant people in our lives. This point goes to the heart of the problematic tension between the human right not to be discriminated against, and the need for protection and support, based on individual preferences and choices. With more sophisticated understandings of the balance between social roles, choices and support systems, policy makers can perhaps respond not just by categorising Derek and Andrew as intellectually disabled or 'other', but by providing social supports and improved life circumstances for all, recognising the everyday, fluctuating identities of everyone in society.

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